



# Poster Boys and the Rehabilitative Dream: Using a Temporal Lens to Explore Severe Brain Injury Rehabilitation

**RESEARCH** 

JULIE LATCHEM-HASTINGS (D)



### **ABSTRACT**

**Context:** The future comes into the present and acts upon the now. Understanding how engagement with the future shapes today and how actions taken in the now affect a time yet to come is important in understanding and improving brain injury rehabilitative practice.

**Objective:** This paper examines the way in which futures of different types of braininjured residents residing in long-term neurological care settings are imagined by health and care professionals and the role a 'rehabilitative imaginary' has in how residents' futures are imagined or go unimagined.

**Methods:** Over 500 hours of ethnographic observations and 49 interviews with staff members in two neurological rehabilitation and long-term settings in England were analysed using situational analysis, drawing out key rehabilitative narratives presented here.

**Findings:** Residents were primarily categorised by their abilities to rehabilitate successfully (or not) and their futures imagined (or not) in line with their rehabilitative journey. Key residents who successfully rehabilitated and fulfilled a rehabilitative ideal were held up as 'poster boys' (or girls), providing a positive advertisement for the organisation, engendered dedication to the specialism of neurological rehabilitation and reinforced rehabilitation-as-process.

**Limitations:** Data was collected in two English care settings. Applicability to international care settings is unknown. Extraneous factors restricting health care professionals' future imaginings were not explicitly studied.

**Implications:** The paper concludes by considering the implications of rehabilitative imaginary-fuelled narratives in these settings. It argues that predominant rehabilitative narratives bracket out how and if the futures of those unable to rehabilitate successfully are imagined by health care professionals and questions whether non-imagining leads to inaction around those not rehabilitating. Potential organisational and structural reasons for constrained health care professionals' imaginings is discussed, and broader applicability of the reification of particular patient types in other areas of health care is considered.

### **CORRESPONDING AUTHOR:**

Julie Latchem-Hastings
Cardiff University, UK
LatchemJM@cardiff.ac.uk

### **KEYWORDS:**

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## **CONTEXT**

Brain injury is one of the leading causes of death and disability in young adults (aged under 40) internationally (Maas, Stocchetti & Bullock, 2008; Clark et al., 2022). Coming without warning and often affecting previously healthy individuals, mortality from severe brain injury ranges from 30% to 50% internationally (Turgeon et al., 2013). However, ever more people with severe brain injury are surviving (Turgeon et al., 2013), and those who do often live with multiple impairments (Schumacher et al., 2016; Azouvi et al., 2017), such as an inability to walk, wash themselves, talk and communicate, eat and drink, or remember and plan. They may have extreme changes in behaviour, experience pain, or have altered or loss of sensation.

Through processes of prognostication, clinicians attempt to make a prediction of the likely outcome of the state and abilities of a patient following injury (Turner-Stokes, 2017). Despite the variety of medical technologies and the in-depth medical study of brain injury and recovery trajectories, clinicians state that there is, nonetheless, 'no reliable way to predict outcome' (Turner-Stokes, 2017, p. 469) early after injury. Subsequently, there is both historic and contemporary recognition within medicine that there is a significant level of uncertainty in the prognostication of outcome following severe brain injury and that the future for these people is therefore unknowable (Gogstad & Kjellman, 1976; Guise et al., 2005; Stevens & Stutter, 2013; Brasure et al., 2013; Turner-Stokes, 2017).

Although this challenge of foretelling futures through prognostication following the early stages post-severe brain injury is well documented, prognostication gives way to a very different set of temporal foci for those who, through medical treatment, have survived severe brain injury and are living with profound and complex impairments in rehabilitation and long-term care settings.

# **BRAIN INJURY REHABILITATION**

Rehabilitation is said to be a future-orientated process which looks to maximise function, physically, cognitively and socially, through restoration, compensation and adaptation while minimising medical complications and disability (Wressle, Oberg & Henriksson, 1999; Kischka, 2004; Gutenbrunner, Ward & Chamberlain, 2006; Meyer et al., 2011; Lowry et al., 2022). However, in severe brain injury, complete recovery is rare, and so, in many cases, despite often prolonged periods of rehabilitation, these people remain impaired and need significant care and support from others in the long term. The extent and multiplicity of their needs and/or issues securing the required funds for complex care to be provided in the community can make care at home not possible, leaving many adults with severe brain injuries residing for prolonged periods of time in rehabilitative and/or longterm care facilities.

Within these settings, some residents have higher needs than others and more severe impairments than others, and some make more significant functional improvements and 'rehabilitate' better than others.

### **COMMUNITY INTEGRATION**

Research over time suggests that 70% of traumatic brain injury survivors are unable to fully re-integrate into their communities due to ongoing impairments (Stergiou-Kita, Dawson & Rappolt, 2011; Binder et al., 2019) and often need ongoing support to maintain community living (Clark-Wilson et al., 2016). Ongoing support services can however be limited or inadequately co-ordinated (Gilworth, 2008; Gagnon, Lin & Stergiou-Kita, 2016), making discharge from care institutions, where care and therapy professionals are on hand, difficult. People with brain injuries can feel unsupported in the initial and longterm process of community integration (Hart et al., 2004; Bay, Sikorskii & Gao, 2009) because long-term support or rehabilitative needs, such as care packages, often funded through social care; speech and language therapy (SALT); supported housing welfare; and educational support are not always available or provided (Kelly et al., 2008; Bay, Sikorskii & Gao, 2009; Holloway, 2014).

A 2021 scoping review focussing on the experiences of people with acquired brain injury and their families highlights that they face significant barriers when interacting and trying to access community-based services (Norman et al., 2022). The review details a series of 'unmet needs', including information about available services post-discharge from the hospital or rehabilitative settings, support for welfare and housing, return to work or education and expert knowledge in the management of long-term symptoms and impairments, for example, fatigue management, pain and psychological issues such as anxiety.

In this paper, I examine the way in which the futures of different types of brain-injured people residing in long-term neurological care settings are imagined by health care professionals. I explore how 'successful' rehabilitation in rehabilitation and long-term institutional places of care is constructed by health and care professionals as a type of rehabilitative imaginary,1 a process where the 'patient' regains meaningful functional abilities through the process of rehabilitation, and how this plays out in everyday talk across the centres and in all staff groups. I discuss how rehabilitation-asimaginary is enacted through the distinguishing of and between resident types—those who are 'rehabable' and those who are not. I note the prevalence of this 'rehabilitative imaginary' when staff talk about their work with brain-injured residents and argue that those who successfully rehabilitate act as 'poster boys', providing a positive advertisement for the organisation, engendering dedication to the specialism of neurological rehabilitation and reinforcing rehabilitation-as-process.

Multiple factors affecting movement from institutional care into the community, staying in that community and integrating into that community may have an impact on how those working in neurological rehabilitation and long-term care imagine the futures of brain-injured people. This paper therefore concludes with a note pondering how broader structural issues might impact staff engagement with residents' futures.

## **METHODOLOGY**

The data analysed in this paper were collected in 2014/15 as part of a PhD using ethnography to explore how the futures of people with severe brain injuries are conceptualised and shaped during their rehabilitation in specialist units. Over 500 hours of observations and 49 interviews with staff members were conducted over a five-month period in two independent sector (non-National Health Service (NHS)) inpatient neurological rehabilitation settings in England: Bracken Lodge and Goodleigh Hall. The two sites were purposively sampled, as both serve patients with acquired brain injury as their largest resident population (although both also provide care for people with a range of different neurological conditions).

Observations included personal care, therapy sessions, mealtimes, social events, meetings and activities in laundries, kitchens, gardens, corridors and offices. Several hundred different residents, staff and family members were observed during the ethnography. Staff interviewed included managers and qualified health care professionals, such as physiotherapists, nurses, occupational therapists, speech and language therapists and care and therapy assistants. 'Hotel service staff'—such as cooks, cleaners, maintenance personnel and administrators—were also observed and interviewed, and their roles in rehabilitation have been reported elsewhere Latchem-Hastings (2021).

Staff, residents and visiting family members were informed of the forthcoming presence of a researcher via a managerial gatekeeper at each site. Posters with a picture of me, the researcher, and the aims of the research were displayed in key reception and shared areas before and during the course of the data collection period. Once on site, I was taken on a tour of the care settings and introduced to staff, residents and family members by the gatekeeper. After that, I introduced myself to any new people I met and explained the aims and purpose of the research as appropriate. I was introduced by the gatekeeper as a researcher from Cardiff University, and the gatekeeper explained that I was researching the rehabilitation of people with brain injuries. I supplemented this introductory information, divulging my background in physiotherapy and giving further details about the research, including its sociological and temporal underpinnings, to anyone who wanted to know more.

I dressed in casual clothes, with long sleeves and scarves—items of clothing which were particularly selected to differentiate me from any clinical staff and did not infer professional status. My presence and the act of ethnographic observations nonetheless initially drew attention, and I was approached with intrigue by some staff and residents. On several occasions, despite the above introductions, I was questioned about my identity. I was asked whether I was from the investigative current affairs BBC programme Panorama and whether I was a health and social care inspector of some kind. In these circumstances, I explained the research aims and the methods at length. Multiple participants took particular interest in the method of ethnography—how data was collected and analysed. I showed excerpts of fieldnotes written about the enquiring person and discussed any initial analytical thoughts I had in the moment. Showing participants how they as individuals were not being judged but that their interactions, along with others', were being described and patterns of practices and discourses being pulled out turned self-consciousness into research interest. These types of discussions also seemed to shift the perception of me as some form of monitor to that of a genuine researcher, interesting and interested in their experiences.

I was initially interacted with carefully, as a stranger; however, due to my frequent presence in the setting over several months at each site, this eventually changed, and I was seen more as part of the team. This can be demonstrated by the 'leaving card' and gift given to me by one site at the end of data collection. I was never ignored during the course of data collection but increasingly included in the life of the site and responded to ever more candidly.

The descriptive act of ethnographic note taking, particularly not attributing meaning in the taking of notes and using temporality as a lens through which to view the data, 'made the familiar strange', which was critical for me as a researcher and a physiotherapist who had previously worked in similar settings to the data collection sites.

Clarke's (2011) 'situational analysis' was chosen and applied to the data. Situational analysis takes elements of grounded theory and discourse analysis to explore 'social worlds'—particular social groupings. Clarke works from an underpinning premise of the existence of 'social worlds' which operate within a particular context (e.g., an institution, community) and also exist as a social grouping in its own right—an allied health profession, for example. Analytical questions posed by Clarke were used to interrogate the data, with 'memos' of themes, ideas and reoccurring discourses being made in response. From a position of data fragmentation, relations between elements (groups, practices, discourses), their nature and strengths or weaknesses were drawn, highlighting and foregrounding the cross-cutting narratives and stories of the 'poster boys' told here.

### ETHICAL CONSIDERATIONS

Ethical approval was obtained from the Social Care Research Ethics Committee, application number 14/IEC08/0014. All participants with the capacity to consent on their own behalf reported on in this paper consented to being observed and/or interviewed. Personal consultees were consulted before the inclusion of those who lacked the capacity to consent on their own behalf, in line with the requirements under the Mental Capacity Act (2005).

## **FINDINGS**

# PART 1: THE REHABILITATIVE DREAM/ IMAGINARY

This section reports on rehabilitative narratives and stories about residents as told by staff at Bracken Lodge and Goodleigh Hall.

The telling of 'successful' rehabilitation stories formed a central part of repetitive and continuous discourse from staff found across observational and interview data. The stories chart a process which leads to restoration of function via small and steady gains or 'big moments' of functional return, for example, a single action which marks a rehabilitation milestone, such as a person's first stand(s) post-injury or beginning to regain speech. Below are three partial examples of such stories. Three different types of staff (a speech and language therapist, a therapy assistant and an occupational therapist) talk about three different residents they have worked with who are considered as having been successfully rehabilitated in one way or another.

When Seb came in here, he had no use of his right arm, and his right leg was really weak. He couldn't bear any weight there. He was in a chair. His behaviour was quite erratic and then we worked with him. With speech and language therapy, he is not going to probably be able to talk, but we have worked with him with communication aids and also with hand signals and gestures. He has become a lot more patient as a person as he has become more settled. Now he is walking around with a knee brace, and he can move his hand more. He can get it from his side up to his chin almost. (Lucy, therapy assistant)

I do cooking sessions with him [Luke]. I do shopping sessions with him. It is about the holistic approach [to] the whole thing, so that helps. The whole thing is getting better all the time when we do our assessment. It is very encouraging. He is now walking and doing exercises, the other day walking on his own without an aid, which is brilliant. He is still walking like a baby starting to learn to walk, but he is walking, which has never

happened for a long time and is huge progress. There are so many success stories in neuro rehab, so many success stories. If I was to talk about them all, we would spend all day talking about them. (Kerem, occupational therapist)

If you look at Donovan after his brain injury, he had two and bit years when he didn't eat anything; he was fully PEG fed. He was so unsafe orally. And within six weeks, he was starting something, and that was a new thing for me. I have never been involved with so intensively with somebody with such a severe brain injury and so low level. You have a few patients who stick in your mind, and that is one of them. On a good day he can eat a full pureed meal with a dessert [and] can have fluids. His family didn't think he would even be able to eat anything ever again. (Orazia, speech and language therapist)

In the extract from Kerem, the occupational therapist, he alludes to having multiple stories to tell, but the telling of such stories at each site centred on a key set of residents. At Bracken Lodge, Luke, Donovan, Daniel and Ezra were the residents who staff mainly discussed, either in the spontaneous telling of successful rehabilitative stories to one another or visitors or when asked directly in interviews to talk about someone whom they have worked well with. Similarly, at Goodleigh Hall, two residents were predominantly spoken about—Sebastian (Seb) and Matthew.

Forty-nine staff were interviewed, and over 100 staff were interacted with during the ethnography. Goodleigh Hall and Bracken Lodge collectively cared for approximately 100 residents, and yet no more than six to eight residents were repeatedly talked about in this way. What was it about these men (all happened to be men), the foci of these successful rehabilitative stories, and what did the telling and re-telling of these stories do?

The characteristics of all these men are similar in that they have significantly progressed physically, cognitively, behaviourally and emotionally to such an extent that all but two are now able to communicate, walk, wash and dress themselves with minimal support and make some choices for themselves. They are all considered by staff to have a good sense of humour and were personable—for example, they readily initiated and engaged in banter and mickey taking with staff. Although these men have many shared characteristics, they differ in age, the severity of their injuries, the mechanisms which have caused their brain injuries and the level of their recovery to date.

Donovan, Luke, Daniel and Ezra are aged between 20 and 30 years, and Seb and Matthew are aged between 40 and 50 years. Some of these men experienced brain injuries due to assaults or road traffic accidents, while others had spontaneous bleeds of the brain (haemorrhages). Seb, Matthew, Luke and Ezra have rehabilitated to levels of either

complete or near independence and have become able to fulfil most 'activities of daily living', to communicate and to make (some) decisions for themselves. However, two of the residents frequently chosen as exemplars of successful rehabilitation residents, Donovan and Daniel, have not reached the functional levels of recovery that the other four men have. These two men have been significantly more impaired following their initial injuries than the others.

Donovan and Daniel had been minimally conscious following their brain injuries and arrived at Bracken Lodge without an established form of communication, with limited movement and unable to conduct any functional everyday task on their own. However, despite the severity of their injuries, both have progressed significantly beyond expectations. Both are now fully conscious, able to communicate either through speech or other established gestures and progressing well physically. Donovan, for example, is just beginning to be able to stand and take several steps with help, and Daniel can partly wash and dress himself and is able to stand intermittently.

One therapy staff member, Clara, recognises the characterisation of this group by herself and other staff and highlights that they form a 'type' of resident. Talking about Matthew and his progression as a successful rehabilitation story, she said the following:

Everyone goes on about how he is almost a totally different person and his behaviour has changed so much. He has made so much improvement in terms of his mobility, and bits of his communication are more reliable. He has done so much that there is not much more being here would do; so in that sense, it is the right thing that his future is looking outside of Goodleigh. ... He can dress himself and go about. He doesn't need a wheelchair anymore. He doesn't need walking aids really, so on the whole pretty independent. ... So a Goodleigh success story, like poster boy Goodleigh, which is good. (Clara, therapy assistant)

Here, Clara picks up that those who rehabilitate successfully are picked out; they become 'poster boys' for the organisation, and their success is harnessed. But what does it take to be a poster boy in a neurological rehabilitation setting, and how are these stories told? Contained within the rehabilitative stories told above (and others like them), there are seven key tenets which make up a poster boy.

# THE SEVEN TENETS OF POSTER BOYS IN BRAIN INJURY REHABILITATION

# 1. Low expectation of further rehabilitative potential The first characteristic of a poster boy success story is an initial low expectation of rehabilitative potential. Staff speak of residents being considered to have reached their

'rehab potential' or reached a point of 'plateau'. This low

expectation is not one made by staff in the current care setting but has come from health and care professionals who have met and worked with the resident prior to their admission to Goodleigh Hall or Bracken Lodge. For example, in an interview with a therapist who was talking about one of the poster boys at Bracken Lodge, she said the following:

I know it was lack of motivation because therapists up to that point had just done everything in bed with him. They had written him off. The doctors had written him off as well, so he wasn't going to have any more [rehabilitative input].

# 2. The challenge and rejection of a negative prognosis

Despite the low expectation of rehabilitative potential which accompanies poster boys into Bracken Lodge or Goodleigh Hall, staff report questioning and testing this. The potential of and hope for progress is therefore not entirely closed and lost, but judgement is suspended, at least for a time. For example, Abram, a physiotherapist, said, 'It was thought. Donovan had reached his rehab potential, but then I just took my own assessment. What can I do? What can he do?' Here, Abram rejects the prognosis given to Donovan as having 'reached his potential' and instead asks himself what he as a therapist can do for Donovan, and he assesses what Donovan can do for himself. This assessment led to the discovery that Donovan did have some active movement. Abram recalled,

OK, he has got a good range of movement in his leg, except in his ankle. Let's start him off on the bike to see if there is any activity. So he had his activity, and we built up a good rehab relationship and bond with him and then continued to progress where he was, standing and things. (Abram, physiotherapist)

Through the rejection of the prognosis which had been placed upon Donovan, Abram was able to identify that Donovan had some muscle activity. The discovery of this small initial ability was then built upon, with the eventual reward of the restoration of some functional return. Here, the practice and process of rehabilitation-as-restoration can be seen.

## 3. Intensity of rehabilitative interventions

Another key part of the story told includes a description of an intense and often lengthy period of rehabilitation. This intense period of rehabilitation is characterised by and emphasised as labour-intensive for everyone, or by a key set of individual staff members, working consistently with the resident. The success of the rehabilitation is repeatedly linked to this period of 'hard work', which is reflected as coming from both staff and the resident himself.

Betty, a therapy assistant at Goodleigh Hall, talked about the rehabilitation of poster boy Seb, stating, 'We've worked so hard to get him to this point.' The point of this telling reinforces the dedication, the consistency and the hard work of both the professional and the resident in achieving this outcome. The desired outcome is therefore not constructed as easy, but as toil, as effort, and is a story of defying the odds through hard work.

## 4. Persistence and 'not giving up'

Alongside the intensity of rehabilitative work, constructed as toil, this intensive period of rehabilitation is coupled with pervasive talk of staff determination, commitment and perseverance in the delivery of their interventions and building relations with residents. A therapy assistant, again talking of Seb's rehabilitation, reflected as follows:

Phillipe [physiotherapist] just kept persisting and persisting. This bloke just wouldn't do physio with him, would not do it. But Phillipe just kept going and going and going because we could all see potential in him. We could see that we could get him at that point where he could live independently again. (Betty, therapy assistant)

Here, staff connect their perseverance with being able to foresee a positive future for these residents. For Seb, staff could imagine a future of him improving successfully enough to live a largely independent life. This imagining is critical to residents' actual futures—as here, this positively imagined future drove them to work hard, to provide intense rehabilitation and to persevere with their rehabilitative practice with this resident. This point will be expanded upon later.

# 5. The demonstration from the patient of consistent progression and improvement in multiple domains

To be a poster boy, residents must display progress, but not any progress will do. The stories told of poster boys always include those residents who have made continuous and functional progress in multiple domains, for example, improving physically, cognitively and behaviourally. This is evident within the story of Seb, as told by a therapy assistant, who said the following:

He came in in a wheelchair, on a one to one, because he was aggressive, and we've got him from not being in a wheelchair [to] going out in the community, communicating with people—now it's not verbal communication, but he can communicate—and to walking. (Betty, therapy assistant)

Here, Betty highlights that Seb has made significant physical recovery, so much so that he can now walk. She explains that he has made significant improvement in terms of his

behaviour, highlighting the significance of this change by explaining that he once needed to have a member of staff with him always 'on a one to one' due to his aggression to now being able to go out into the community. She also highlights that he is now able to communicate, although not verbally. The establishment of a consistent form of communication is also highlighted as a key progression made by Seb by other staff members in their stories about him. This pattern of achievement across multiple domains is seen in each poster boy story, every time one is told.

# 6. Improvement that makes discharge home or into the community possible

To be a poster boy requires more than improvement in multiple domains and recovery beyond prognostic expectation; it requires improvement to such a degree that going home or being discharged to live in a 'community'<sup>2</sup> setting becomes possible. All poster boys had the potential of being able to be discharged from Bracken Lodge or Goodleigh Hall due to now being able to do much for themselves and/or no longer needing the level of care, rehabilitative input or specialised input provided at Bracken Lodge and Goodleigh Hall. At the time of data collection, Seb was being actively discharged, and another poster boy, Ezra, had recently been discharged home. The legacy of the success of Ezra's rehabilitation was evident throughout the three months I was present at Bracken Lodge, as staff repeatedly told me about him and relived both the process of his rehabilitative progress and the moment of his leaving. For example, the story of Ezra was told to me in an interview with an administrator, who recalled the following:

Ezra was wheeled in, and day by day the physio he received, it was phenomenal, you know, because he was in a chair. Just seeing him getting out of a chair and taking a couple of steps and then going from one end of the corridor to another and then going around the block, ... it is amazing. And he walked out, yes, no stick. It was lovely. It was really, really nice; even his speech, because that was quite affected as well, but that improved, and it was really lovely, really nice to see it. His wife came and got him, and that was nice. I mean he was tearful. Everybody was tearful. But, you know, that is the sort of thing that is nice. (Maxine, administrator)

This moment, as can been seen in the telling of it by Maxine, is full of emotion by the teller. While the words within the quote above note the feeling of both the resident and staff, what is said does not portray the joy with which this was spoken at the time.

Even if discharge home or to a domestic environment was not currently in the planning, the likelihood or the expectation that home or living in the community would be the outcome for these residents was always muted. For example, Matthew has made vast improvements in multiple domains and is the resident to whom the name 'poster boy' is initially attributed. On asking the staff member who had referred to him in this way, what she foresaw for his future, she describes foreseeing him living in a setting away from the neuro rehab centre, but not alone and requiring ongoing support and the opportunity for constant interaction with others.

### 7. The sustaining of rehabilitative progress

To be a poster boy, it is not good enough to just improve and be restored. Restoration must be lasting. The sustaining of rehabilitative progress is critical. Many residents had progressed significantly since their admission to Goodleigh Hall and Bracken Lodge but were not considered poster boys. Patients such as Eddie and Cynthia, for example, had made significant improvement during their time in the centre, but they had also experienced decline. Despite their initial rehabilitative success, their decline ruled them out of qualifying as a poster boy. Ara, a therapy assistant, reflected on Cynthia's deterioration:

Since I started here, she's gone, completely deteriorated with her orientation. Her proprioception's terrible. When I first started, she was walking daily with the physio. She barely goes on the bike now. It is quite sad to see. There is a massive change in a year; it is really sad.

Despite their deterioration and the level of care these residents required, there are plans for these residents to go home. As Crysta, a health care assistant, remarked, 'I'm excited for Eddie. He's going home with Myla [his wife]. He's going to be in the best care he can with Myla because she loves him, and they're going to have a nice little place together.' In each of these cases, however, home is only being made possible because of dedicated family members willing to provide significant levels of care for their family member. Being a poster boy then requires not only rehabilitative progress of functional return but also the long-term maintenance of it.

### **POSTER BOYS**

This concept of a 'poster boy' is central to explaining how and why these successful rehabilitative stories are told. A 'poster boy', 'poster girl' or 'poster child (US)' is defined in two main ways: first, as a person who appears on a poster for advertising and marketing purposes, and second, a person who typifies, epitomises or represents a key characteristic, quality, movement, cause or ideal (Collins Concise English Dictionary, 2013). In this sense, the person appearing on the poster is labelled as an embodiment or archetype, and their identity is synonymous with the associated ideal or representative of its most or least favourable aspects.

In the United States, however, there is less emphasis on a definition surrounding poster girl or poster boy; instead, they use 'poster child'. The term originally referred to a child afflicted by some disease or deformity whose picture was used on posters or other media as part of a campaign to raise money or enlist volunteers for a cause or organisation. Such campaigns may be part of an annual effort or event and may include the name and age of a specific child along with other personally identifiable attributes. Notably, this convention was used by the Muscular Dystrophy Association. Jolene Kay Worley became the first National Muscular Dystrophy Poster Child in 1955.

The men that have been discussed act as 'poster boys' in rehabilitation and the independent health and social care business in three main ways. First, they typify the ideal successfully rehabilitated patient and therefore promote rehabilitation as a process (and the professionals who are delivering it). Second, they are an advert, a marketing tool for the promotion of the service, for the company providing the rehabilitation. This is particularly evident in independent sector care settings (for-profit organisations), where the poster boy or girl can be seen on marketing materials, on leaflets and brochures and, most notably, on websites which promote rehabilitative services. Faces of residents sit alongside 'testimonials' which make successful claims to their progress and recovery; these statements are made by either the residents themselves or their families.

There is also a third element to being a poster boy in this context. Poster boys and girls can be used as examples which typify the characteristics of a disease or impairment and are used to raise awareness or money for assisting those with an illness or impairment, or they are held up and used as case studies to be medically examined.

The holding up or putting up of these poster boys and girls is literal in some medical contexts and is particularly evident in dysmorphia clinics, where pictures of people with some genetically caused deformities are photographed and displayed on walls or in presentations for discussion and analysis by medical teams. This practice and what it accomplishes in terms of its role in the categorisation of conditions and diagnoses has been described and analysed by Latimer (2013). There is then a cultural and historical context of holding up certain types of patients—the poster boys or girls—both in the form of the medical case study and as an advert.

# PART 2: IMPLICATIONS OF REHABILITATIVE NARRATIVES ON RESIDENT FUTURES

As highlighted in Part 1, those able to fulfil the rehabilitative dream are held up as poster boys (or girls) for successful rehabilitation—their stories being told and retold. In Part 2, I discuss the implications of the prevalence of narratives underpinned by the rehabilitative imaginary, both for those who can fulfil it and for those who cannot. I do this with particular focus on how the futures of these different types of patients are imagined.

During data collections, towards the end of each interview with staff members, they were asked to think about residents in their care and to select several and talk about what they thought their futures looked like. Despite the potential selection of three broad categories of residents present in the care settings—(1) those who were deemed rehabable, (2) those who were deemed not rehabable, and (3) those who were dying—those most readily selected for futures' discussions were poster boys.

At Goodleigh Hall, the future of poster boy Seb was most frequently referred to and thought of first. Seb's future was always constructed as leaving the setting, going home or back into the community and living independently. For example, Mercy, a therapist, said, 'Ideally the future would be him moving on to some supported living environment.' Seb's future, then, is imagined as a point of discharge, but the details of a future beyond his new place and type of abode went largely unspoken.

Other staff spoke of poster boys' futures as extending outside of a point of discharge home or an alternative location. For example, Kerem spoke of poster boy Luke, saying the following:

He is going to be able to maybe change from being a motorcycle mechanic maybe to a motorcycle mechanic tutor. ... Still within the motor link and its field, but it is a different call, a step back, and then [he] can instruct others. This is what I envisage to be his future. This is what I see. ... You may not do exactly what you want, but you will do something near. (Kerem, occupational therapist)

Here, Kerem imagines future activities for Luke to work towards and a potential for future employment. However, he also explicitly states how his work with Luke is not necessarily about creating a future that Luke would ideally want but trying to make a future that is as near as possible to the future Luke imagined for himself prior to his brain injury. Kerem works to achieve this by working through Luke's interests to reshape an alternative but linked future.

In contrast to poster boys, staff often struggled to imagine a future or construct an alternative future for residents who were not showing significant rehabilitative progress. For example, on asking Maddie, an occupational therapist, to think about what the future looked like for a non–poster boy resident, she said, 'You sort of want to pick someone a bit more positive (laughs) you know. Um, oh my gosh, it is so hard to try and imagine actually.' However, after long pauses in interviews and significant thought, staff could offer some thoughts about what life may look like for others they cared for.

Aside from poster boys, one female patient and a young male patient with more severe impairments were mentioned as having futures. These residents were not making consistent or rehabilitative improvement across multiple domains, but they were making progress in

some areas. These residents were able to demonstrate clear and consistent, albeit slow, improvements in terms of returning awareness or function in these two cases.

One resident, Marta, was considered by a health care assistant Philippa to be 'coming along leaps and bounds', as she had recently been able to manage a couple of mouthfuls of food, had started using a speaking valve and had regained some small movements in her arms and legs. Staff imagined that the future for this resident would see her making slow but continual functional improvement which could lead to the removal of her tracheostomy, an ability to eat and drink some food and fluid and the ability to communicate verbally. Although spoken tentatively, a broader future was imagined for her by one therapist, Mercy, who said, 'If we can get her weaned off her trachy, she is a possibility. I think there is a chance she could be supported in the community.'

Aside from Marta, Maddie, an occupational therapist, spoke of a male resident, Lee, who is in a minimally conscious state. Reflecting on a recent assessment she had been involved in carrying out, she said the following:

We are seeing there is some tracking. We're seeing some good response to oratory stimuli; so I would be interested to know if we can harness some of that [...] when you are giving him things. He's maybe not making the choices, but he is aware that there are two things in front of him because he looks from one to the other. But you have asked him to look at the ball. He hasn't done that. He's not following the command, but he knows there are two things. ... For someone like him, ... I [could] give him back some quality of life if he is able to look between two things and make him start selecting something. So ... can I hold up different pairs of trousers and would he choose. (Maddie, occupational therapist)

Here, Maddie explains that following a sensory assessment, it has been established that Lee has some awareness of his environment. She explains that when two objects are placed in front of him, he can look between them. Because Lee can do this, that opens up a further potential which enables Maddie to look onward, to think about and imagine the possibility of Lee being able to identify the objects and, eventually, maybe make a choice between them. She explains that if he can make a choice and indicate his selection, this may enable him to have some control over his environment. However, Maddie identifies that a future for Lee, and other residents like him, is limited:

No matter what you do or what change you see, it doesn't change the care needs. There is the profound disability and impairment there, and it will always be—can I say it will always be? Pretty much. You can pretty much say it will always be full hoist with assistance of two, full rolling, full

bed bath with the assistance of two, wheelchair user, attendant propelled wheelchair user. That outcome doesn't change. And it is like, yes, but if you have gone to the effort to find out someone has got some awareness and some consciousness, you should give them some sort of life associated with that, even if it is just a little preference around, you know, making some communication choice. So, I would like to give him a crack and see where we get with him. That would be my best hope, to see if somehow I could give him a means of demonstrating preference. (Maddie, occupational therapist)

Here, Maddie both opens the future for Lee and then immediately closes it down. She highlights how his recently established awareness of two objects may lead to the opportunity for communicating choice in the future; however, at the same, she explains that no matter how much he may progress in terms of communication and choice, his life will remain largely the same. The level of impairment and his needs will remain.

While a future could be imagined for those who were either rehabilitating well (poster boys) or making consistent progress, the future for residents who were not making active rehabilitative process was never spontaneously spoken about. Only through direct probing in interviews and asking staff to consider the futures of residents did any mention of the futures of those with severe impairments who were making little or no functional progress get discussed.

# **DISCUSSION AND IMPLICATIONS**

This paper has reported the pervasiveness of the rehabilitative dream in the talk of staff in neurological rehabilitation and long-term care settings. It has highlighted how one type of rehabilitating resident acts as a 'poster boy' for the rehabilitative imaginary. Poster boys and their 'success stories' advertise the rehabilitative service provider but also promote rehabilitation as a process and the rehabilitative therapies and specialisms which make up rehabilitative care.

Residents who are able to show rehabilitative progress (regaining the functional abilities lost through brain injury) have a future, in that a future is imagined more readily for them by the staff who care for them. The future comes into the now by guiding action in the present—an imagining of a future predicates action. In this way, the rehabilitative dream narrative encourages action around these patients and may in turn support the bringing to fruition of the imagined future.

The futures of other residents, unable to rehabilitate in the same way as poster boys, were largely unimagined and were considered very difficult for staff to imagine. The pervasiveness of the rehabilitative imaginary in these places of care then affects the way in which futures for other residents, unable to rehabilitate, are imagined and if they are at all. The rehabilitative imaginary brackets out an imagined future for others and closes down the horizons for those who do not and cannot be poster people.

For those who are unable to progress and will not make any further recovery, futures are rarely imagined at all. When pushed in the interview to think about the lives of non-rehabilitating residents, staff spoke of their lives as an extended present and explained how they focus on 'quality of life' for these residents in the now, tomorrow or next week. Lives for these people then are temporally restricted, being imagined in weeks and months only. How open or limited a resident's future is imagined mirrors the ebb and flow of an individual's rehabilitative progress.

While the future can seem closed to residents unable to show progress, if they do show signs of recovery, a future can be and is then reimagined for them. Future imagining is therefore not static but is in a constant state of flux. For residents who do not fit the rehabilitative dream (and are not dying), the imagining and working towards a future that is as open as the future of a poster boy can however be somewhat buoyed. A future can be imagined and opened up if residents have the unfaltering support of their families. Families who are committed to providing practical and emotional support can make it possible for those unable to be largely independent to be safely cared for outside of Goodleigh Hall and Bracken Lodge. Through family support, futures can be imagined for those who have severe impairments and are *not* making rehabilitative progress.

While the pervasiveness of the rehabilitative dream, which is the outcome for only a fraction of those within the walls of Bracken Lodge and Goodleigh Hall, help to hold up hope—and the morale of staff—this ideal is disproportionate to the reality of rehabilitation in these places and can act to bracket out the imagining of the futures of those who cannot fulfil the rehabilitative dream. Critically, these non-rehabilitating people require an alternative future be imagined for them and by those who work with them.

This study specifically examined brain injury rehabilitation, but the imagining of futures and their role in care, rehabilitation and discharge processes from health and social care services will be applicable across conditions. Paying attention to who gets 'held up' as examples of positive or 'good' outcomes across rehabilitative services and who does not and using temporality—particularly examining how patients, families and health care professionals imagine and engage with the future—provides a lens to see how rehabilitation is experienced, how it is done and who it is for.

# **LIMITATIONS**

Extraneous factors restricting health and care professionals' future imaginings were not explicitly studied, but it is plausible that future imaginings,

especially for the more severely impaired residents, are heavily impacted by the availability of ongoing support in the community and the accessibility of the world outside the walls of the institution, which is reflected in a long history in community integration and disability studies literature. Staff participating in this study were regularly involved in discharge meetings and processes with external social, care and education agencies and will have been aware of limitations, such as available accommodation, care support and opportunities for work or education.

There are however some professionals, such as social workers and independent brain injury case managers, who regularly support complex brain-injured patients to live in their own accommodations. It is possible that such professionals, with enhanced community services knowledge and access to finances (e.g., following personal injury litigation), may have broader imaginations when it comes to envisaging the futures of brain-injured people.

Data was collected in two English care settings. Understanding how health and social care professionals and care staff internationally engage with the future and imagine the futures of brain-injured residents and how this may differ in relation to role types and professional experience, available ongoing services and social support is unknown.

## **NOTES**

- 1 The 'imaginary' or 'social imaginary' refers to the set of understandings, practices and common expectations that characterize the community (Anderson, 1983), 'the ways people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations' (Taylor, 2004, p. 23).
- 2 Staff refer to 'the community' as a non-institutional setting, such as the family home, a small group home, independent living with warden-controlled support, etc.

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# **COMPETING INTERESTS**

The author has no competing interests to declare.

### **AUTHOR AFFILIATION**

**Julie Latchem-Hastings** orcid.org/0000-0001-6738-916X Cardiff University, UK

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